

MCH/CSHCN Director Webcast -- April 2003

>> Good afternoon from the Parklawn building in Rockville and welcome to the third in our current series of MCH.com WebCasts.

Dr. van Dyck is traveling at a meeting in England this week so he's unable to be here.

I'm filling in for him.

I'm Chris DeGraw.

We have an interesting Webcast today.

The first item on the agenda will be a national survey of Children with Special Health Care Needs. As you know, that has been on the tentative agenda for the 12th of programs and we're glad to have clearance to finally talk to you about it today.

We then will have a presentation on the MCHB sponsored breastfeeding promotion and physician office practices program at the American Academy of Pediatrics and a presentation on national breastfeeding campaign.

I'll introduce our speakers prior to each presentation.

Some housekeeping chores.

First, some of you will notice that the interface may look a little different this time.

It's because our colleagues at the University of Illinois-Chicago have phased in a new system and you all should be on the new system.

The slides will appear in the central window and advance automatically.

They're synchronized with the speaker's presentation.

You don't need to do anything to advance the slides.

You may need to advance the timing by using the plus and minus buttons at the top right of your screen.

We encourage you to ask the speakers questions at any time during the presentation.

Simply type your question in the white message window on the right of the interface, select question for speaker from the drop-down menu and hit send.

Please include your state or organization in your message so we know where you're participating from.

The questions will be relayed to the speakers periodically throughout the broadcast.

If we don't have an opportunity to respond to your question during the broadcast, we'll mail you afterwards.

Submit questions any time during the broadcast.

On the left side of the interface is the video window.

You can adjust the volume of the audio during -- using the volume control slider which you can access by clicking on the loudspeaker icon.

Those of you who selected accessibility features when you registered will be text captioning underneath the video window.

At the end of the broadcast the interface will close automatically and you'll have an opportunity to fill out an evaluation.

We appreciate the feedback.

Your responses will help us plan future broadcasts in the series and improve our technical support.

So again, welcome to the third in our current series of Webcasts and we'll get started with our first presentation.

First presentation is about the National Survey of Children With Special Health Care Needs and our presenter is Michael Kogan.

Michael.

MICHAEL KOGAN>> Thank you very much, Chris.

This presentation was originally going to be given by Dr. van Dyck until he had to go to England. So I was drafted to fill in for him.

Try to imagine Barbara Streisand in "A Star is Born" and you can imagine how I feel.

So when I talk about the Children with Special Health Care Needs survey and I only have 20 minutes to talk about it so I'll try to go through it rather quickly.

We have a lot to go through.

The survey is a partnership between HRSA's Maternal and Child Health Bureau.

It has used since the early 1990's.

We used that mechanism to find 750 children Children with Special Health Care Needs in each state.

This number is derived out to provide reliable estimates.

The data was put up on the MCHB and MCHS website a couple months ago.

There are two main reasons why we did the survey.

The first was to establish uniform state, regional and national estimate with children Children with Special Health Care Needs under 18 using the existing children special health care needs definition.

This is the first time we've ever been able to do that in the United States.

Before that, we derived estimates of this important population from the national health interview survey.

Those were just guesstimates.

The second reason was to provide state, regional and national data for this population and their systems and the impact and baseline estimates for federal and state performance measures, the Title V needs assessment activities and Healthy People 2010.

For this survey we screened almost 200,000 households with children.

We screened about 375,000 children for special health care needs.

About 39,000 interviews were completed of kids categorized as having children's special health care needs.

In the outline of this survey we had the prevalence of children's special health care needs was determined by a screener that I'll talk about in a minute or two.

As you see on the screen there were a number of other areas such as health insurance coverage, I'll provide highlights from most of these areas in this presentation.

Children with Special Health Care Needs are defined by the Department of Health and Human Services as those who have or are at increased risk for chronic physical, behavioral or emotional conditions and who also require health related services of a type or amount by that required by children generally.

This was the definition derived by MCHB in conjunction with a number of organizations in 1998.

Now, to translate that operationally we had a living with illness screener.

The screener was to identify Children with Special Health Care Needs.

Whether a child used more medical care, educational services than usual for most children of the same age.

Was this child using mental health counseling or prescription medication or whether this child was limited in his or her ability to do things most children the same age can do due to a medical, behavioral or other condition that is expected to last at least one year.

I think the important point here, there is a crucial decision made during the design of the survey. You see with children with special health care needs the emphasis is focusing on consequences of the condition rather than a list of chronic conditions as was done in previous surveys.

Because research has shown that parents are not the best reporters of their child's chronic condition.

Now looking at the prevalence of children Children with Special Health Care Needs we find that about 13% of kids in the country could be -- are classified as having a special health care need and here I need to give you a caveat.

After the data were made public on the website, we found a slight problem with the weighting scheme.

Weight so it allows you to go from a sample size to be representative of the country.

We're in the process now of reweighing the data and we expect there may be slight changes in the final numbers.

So please don't use these as final but rather close to final.

Now as we look at the prevalence of special health care needs by age, you see a major jump between the group 0 to 5 and 6 plus.

This is because of diagnosis when kids get to school age or a number of problems aren't seen until the child enters school.

That may be ADHD, it may be learning disabilities and such.

When you look at the prevalence by race and ethnicity you see there is very little difference between non-Hispanic whites and non-Hispanic Blacks.

Hispanics have a much lower prevalence.

Most surveys show that Hispanics have significantly -- are significantly less likely to be -- have health insurance coverage.

So this may be a result of diagnostic bias that they have less access to care and less access to being diagnosed with a condition.

This is something we have to explore further.

Now when we look at by household, you see that among households in the U.S. who have children, one in five of those households have a child with special health care needs.

Now looking at the health and functional status of children of special health care needs, this population as you can imagine is quite diverse.

It includes children with a wide range of conditions, are varying levels of impact, from the child being severely limited to a child, let's say, who is taking medication for a condition but their normal activities aren't impaired.

Now we look at from now on the rest of the data I'll present is presented only among the population of children Children with Special Health Care Needs.

So we see that the proportion of children Children with Special Health Care Needs by far the biggest need among this group was kids in this group using prescription medications.

Almost 3/4 of them.

Surprisingly over 1/4 of this population has need or use of emotional, behavioral or developmental services.

Now going to health insurance coverage you all have a picture there of three teens looking way cooler than either you or me.

And health insurance, as you know, is an essential ingredient in access to care.

Kids who don't have health insurance are more likely to forego necessary preventive care and acute health care.

Now we'll talk about the findings on health insurance.

We found that among children Children with Special Health Care Needs about 12% of this population was uninsured in the past 12 months before the interview.

This is in the range of what other surveys have found for uninsured among children.

Now, when you look at it by race and ethnicity, you see that Hispanics are significantly more likely to have been uninsured.

Again, as I mentioned earlier, this is a finding you see in most studies on health insurance.

Now, we weren't just looking at whether a child had health insurance or not, but how adequate the coverage was.

And I think here we make a very unique contribution because this has been a rather under studied area.

Now, as you see on this slide, when you look at all criteria for adequate insurance it's about 2/3 this population.

We use three criteria to judge whether a child had adequate health insurance.

Whether they -- the parents considered that they had adequate benefits, whether they had access to needed providers, and whether the charges were reasonable.
And as you can see, when you look at adequate insurance by income level you see a distinctive income gradient.

Over 40% of families who were less than 100% of poverty had inadequate health insurance compared to only 28% of families at 400 plus federal poverty level, which is still quite high.
Now, going to the section on health care needs and access to care.

This survey -- this section of the survey focused on unmet needs because children with special health care needs require a broad range of services.

Families may need additional services such as respite care, genetic counseling.

So when we look at the percent of children with special health care needs with unmet service needs we find that almost 18% of this population had at least one unmet health need.

When we separated by insurance type, looking at uninsured, as you can guess is where the problems really stand out in.

This population, almost half of the kids who are uninsured had at least one unmet health need.

Now going to the impact on families, I think the findings in this section are quite striking.

When I talk about the impact on the families, I'm referring to either the family's finances, their employment status or their mental health.

This section is going to describe the impact that children with special health care needs of on their families.

Their time spent caring for their children and the impact of the children's needs on parents' employment.

Now, when we look at time spent providing, arranging or coordinating care for children with special health care needs per week, 13 1/2 percent of this population spend their -- their families spend 11 or more hours a week working on their child's care.

An additional 6.7% spend six to 10 hours per week.

Now, when we look at the percent of children with special health care needs whose families spend 11 hours per week and look at it by income level the findings are really rather striking.

For families less than 100% of poverty level, a quarter of these families spend 11 or more hours a week taking care of their child compared to only 6% of families in the highest income level.

Now, one thing that you don't see on the charts that were given is we also looked at by severity of condition.

Again, the findings are just as strong as you would expect.

Kids who have the most severe conditions a much higher percent of families spend 11 or more hours a week taking care of their child.

Now, we look at the percent of children with special health care needs whose families experience financial problems due to the child's condition, you see over 20% of families say they have financial problems because of their child's condition.

And again, you find -- you have the same findings when you look at it by severity of condition.

When you look at it by insurance type, you see that again families without insurance are over 40% -- over 40% of families without insurance say they've experienced financial problems caring for their children -- their child.

When we look at the impact of a child's condition on the parents' employment, and this I find -- when I first looked at the data I find it was incredibly powerful to me.

You find that 30% of families either stopped working or cut back on their work because of their child's condition.

When we look at by income level, again you see this -- a major gradient.

About 43% of families in the lowest income level either stopped working or cut back on their employment compared to about 20% in the highest income level.

Why might that be?

There could be a number of reasons.

It could be a lack of coordinated care leading to greater time commitments and then with greater time commitments having to cut back on work.

It could lead to a family having to reduce their income level.

Again, you find the same gradients on the severity on the child's condition.

What comes across from these findings on the national data is we find major gaps in our system of caring for children with special health care needs, particularly those in poverty, particularly those with the most severe conditions are where you find problems with coordination of care and satisfaction with care.

Now, a lot of the data I presented comes from a chart book that we're going to talk about.

The chart book also has state data, a page for each state.

And as an example I'm going to show you the page for Michigan.

Our book is in the final stages of production and everyone in the audience should be receiving a copy of the chart book in the relatively near future.

So thank you very much.

CHRIS DEGRAW>> Thank you, Michael.

At this point there are no questions for Michael, so we'll proceed to our second speaker.

Don't hesitate to send in your questions for any of our speakers and we'll have another opportunity at the end of the broadcast to field those questions.

Our second speaker comes to us from the American Academy of Pediatrics in Illinois.

Her name is Betty Crase and she's going to be talking about the office practices program.

Unfortunately you won't be able to see Betty herself since she's hooked in by telephone but you'll be seeing her slides on the screen.

Betty, would you like to go ahead?

BETTY CRASE>> Yes.

I'm delighted to be with all of you this afternoon even if it has to be by telephone.

The first slide should show two beautiful babies looking at each other.

You might think that they're asking, what is it all about?

That's what I want to do this afternoon is to give you a very quick overview of what the breastfeeding promotion in physician's office practices program is all about.

Of course, this is done in partnership with the Maternal and Child Health Bureau and Denise Sofka is the project officer and I'm delighted that she's with us here today, too.

The first goal in the program is to increase the number of pediatricians, obstetricians, family physicians and other health care providers who effectively promote breastfeeding in ethnically diverse populations toward achievement of Healthy People 2010.

I'll break it down and give you more details.

There are five objectives under goal number one.

We'll take a look at the first objectives now.

The first objective is to enroll 300, a minimum of 300 pediatricians, obstetricians and family health care providers with racially and ethnically diverse background and those working with underserved populations in the program.

I want to tell you a little bit about the enrollment criteria before we go into the statistics that -- or the data that has been collected on the total enrollment.

For our enrollment criteria, applicants from the American Academy of Pediatrics were held to a standard of a patient population greater than 50% diverse or non-white.

For applicants from other organizations outside of the American Academy of Pediatrics the patient population was allowed to go to a greater than 25% diverse or non-white.

It was done because the majority of the applicants did come in from the American Academy of Pediatrics I think due to more widespread promotion of the program than what might have occurred in the other organizations with whom we were partnering.

You'll hear more about them in few moments.

Let's take a look at the total enrollment figures.

To date we've had 694 individual applications received from maternal and pediatric health care professionals.

Of those, 350 of the applicants have been enrolled so we've actually based on the criteria that I just gave you, have enrolled 50% of the applicants.

You'll notice on your slide that there were seven voluntary withdrawals.

We have had some individuals whose circumstances have changed and they have had to leave the program and we wanted to report their voluntary withdrawal leaving us with currently 687 applications active.

Of those applications, 432 of the applicants are AAP members.

That's 62%.

With 259 of those AAP members enrolled.

That's 74%.

Lest you think only AAP members are active in this program I'm delighted to say we've had a good representation from the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, from the National Association of Pediatric Nurses and Practitioners.

Those have been the organizations who have given us the most applicants outside of the AAP. Other organizations represented are the Academy of Breastfeeding Medicine, the Indian Health Service, maternal and child health representatives.

The National Hispanic Association and the National Medical Association.

You can see we have had quite a big draw.

Actually if you would look at -- you don't have this in front of you.

If you would look at the total non-AAP applications received based on organization, the number becomes 764 because a number of these individuals belong to multiple organizations.

I thought you also might like to know that we did track the application practice settings and show 45% of all applications received were from large group practices.

And we define that as four or more physicians.

Actually, some of these practices are huge.

They are institutions, they are hospitals, academic settings and they have 20 or 30 participating physicians and support personnel involved in the program.

22% of our applicants have come from small group practices made up of two physicians, two or more physicians.

20% are solo practices, and 13% fit in the other category.

In most cases just not indicated on our application form.

Now let's look at objective 1B which is determine and compare breastfeeding attitudes, knowledge and management skills of the 300 program participants through the baseline and follow-up years, administration of the physician self-assessment questionnaire.

Adapted to capture cultural competence and behavior changes.

This is our means of determining physicians' attitudes, knowledge and actual skill levels regarding culturally sensitive breastfeeding and support.

It is multidisciplinary, meaning that it is appropriate for all of our various maternal and pediatric care providers to fill out.

It is culturally sensitive and proud to say we've worked with the National Center for Cultural Competence in the development of not only this evaluation tool but the other tools I'll be mentioning shortly.

Right now, our physician self-assessment questionnaire, along with our other evaluation tools are under institutional review board review.

They are a pre-test, post-test design and you'll see from the objective that we are going to be looking at the data that is collected before and after.

In other words, at the beginning and the end of our educational program that I'll talk about pretty shortly here, too.

You should be seeing at this point a slide -- a really beautiful slide of children reaching out to each other.

Of course, our children are our eager and want to learn more about each other and that's what I hope that this program will be doing for all the health professionals and public health representatives out there, to make us more sensitive to each other and to our needs with a special focus on breastfeeding promotion and support.

Let's take a look at objective 1C, to distribute up to 15 technical and educational to help program participants more effectively promote, support and manage breastfeeding in their medical practices.

I'll quickly go through the various publications that have either been adapted or developed for this program, or are under consideration.

There are a number of AAP publications being adapted.

Including a piece called "the 10 steps to promote parents' choice to breastfeed their baby."

Checklist for breastfeeding help supervision.

Patient as well as professional materials including a woman's guide to breastfeeding.

We have a newsletter available to all the program participants entitled "breastfeeding best for baby and mother's.

We have a parent book put out last year by the academy.

I'm proud to say the AAP and ACOG are working together to develop a user friendly handbook for physicians entitled, "breastfeeding handbook for physicians."

We believe it will be an important piece available later this year.

We have a speakers kit on breastfeeding promotion and management which includes the ten-step piece I just mentioned.

In addition to that there will be approximately 80-slide Power Point presentation included in the speaker's kit as well.

I'm delighted to say the Department of Health and Human Services Office on Women's Health will be funding that project for us.

It will be not only included in our breastfeeding promotion and physicians office practices program but also will be available for health professional education and support in conjunction with the national breastfeeding awareness campaign that you'll be hearing about when I'm finished.

We have AAP policy statements that will be included in our package of resource materials.

As well as a variety of materials that have been provided to us from our project advisory committee.

Of course, one of the most important being the HHS blueprint for action on breastfeeding.

So there are a number of pieces that are going to be available and we hope to be able to individualize the resource kits that the participants in the program will be receiving based on the type of practice they have.

In appreciation at the end of the program we will be giving certificates of achievement for breastfeeding for physicians to give to mothers.

These will be in English and Spanish.

And also we have the gold lapel pin signifying breastfeeding is the gold standard in infant nutrition to be given to the physician.

Going on to objective 1D.

Provide technical assistance in breastfeeding emotion, support and effective managing assisting them to utilize publications and products provided through the program.

A little bit about our technical assistance.

We've had 623 requests for technical assistance since the beginning of this grant, October 1 2001.

The major categories of questions are breastfeeding materials, breastfeeding recommendations, the medications questions, information about policy statements and, of course, information about the breastfeeding promotion and physicians office practices program itself.

It's why you see that phase 2 there.

Who actually contacts us?

Well, physicians and other health care professionals are the number 1 and 2 folks who contact us.

Followed by parents, other organizations, students and then the media.

All media calls are given to the AAP PR department to handle.

Going on to the last objective in this series, through the use of the parent survey tool, track changes in breastfeeding initiation and participating medical practices before and after the educational and technical assistance interventions.

This -- the parent survey tool is administered by the physicians to mothers at their six-week postpartum checkup, or at the one-year well baby checkup.

Both of these are given over a specified one-month period.

There are 21 questions on this survey and it will look at the duration of exclusive breastfeeding as the initiation rate in that particular practice.

This also is in the IRB.

Institution Review Board review right now.

Then we'll go on to goal 2 after seeing a couple of lovely mothers breastfeeding their babies.

This second goal is to develop strategies to bring health professional organizations and public health representatives together around breastfeeding promotion and support to increase the incidence and duration of breastfeeding and decrease racial and ethnic disparities as determined in the Healthy People 2010 goals and objectives.

Objective 2A, just two under this goal.

2A is to engage representatives from up to ten health professional organizations and public health service providers in a collaborative network to meet the needs of racially and ethnically diverse populations by a formation and utilization of a multidisciplinary project advisory committee.

We're extremely proud of our pack, as we call it.

The goal said to bring up to ten.

We actually have 11 organizations who are working together.

Some of them for the very first time.

Around the issue of breastfeeding.

Our pack members include the Academy of Breastfeeding Medicine, the American Academy of Family Physicians.

The American College of Obstetricians and Gynecologists.

The Maternal and Child Health Bureau.

The National Hispanic Medical Association, the National Medical Association, the National Work Association, and the USDA Food and Nutrition Service.

Objective 2B is to facilitate the development and maintenance of regionally focused action groups geared toward breastfeeding initiatives in underserved populations in each of the ten federal regions.

This is a very exciting aspect of this program.

We're gearing up for it right now.

We're accomplishing this collaborative and networking opportunity via electronic mailing lists.

By a list serve.

One to be established in each of the ten federal regions.

I thought you would like to know that all the state MCH directors and the children's -- we look forward to having your participation along with all the maternal and pediatric health care professionals who are on board.

You'll be joined by our project advisory committee, by the volunteer network of AAP chapter breastfeeding coordinators and all the USDA regional nutritionists and many of the WIC coordinators.

We'll be able to welcome in addition community health centers, rural and migrant health centers, healthy start personnel as well as early head start folks.

These list serves promise to be extremely exciting and we're hoping to kick off this collaborative networking opportunity within about a month.

I wanted to quickly sum up by taking a look at our outcome measures for this program.

And they include to administer the physician self-assessment questionnaire at the program beginning and end.

To determine the breastfeeding initiation and duration rates in practices at program beginning and end and compare them with the Healthy People 2010 goals through the use of the parent survey tools.

Those who do complete this evaluation measure will be given their own initiation duration and exclusive breastfeeding rate which will be compared with the entire set of rates that come in from the full enrollee group as well as comparing all of that to Healthy People 2010 so we can see how far we've come in this program and I suspect how far we still will need to go.

We'll be tracking the number of physicians participating in the program as well as tracking all the technical assistance that is provided.

And we will, at the end of the program, be assessing the effectiveness of the overall package, including the educational resources provided to program participants.

This will be done through a program evaluation survey which also will have IRB approval.

At that you should be seeing two babies who now understand what it's all about and I hope I've been able to enlighten you, too.

Thank you.

CHRIS DEGRAW>> Thank you very much, Betty.

If anyone has any questions for any of our speakers please submit them at this time.

Otherwise I would like to thank all three for helping us out and helping us bring this important message to you.

I want to thank all of our viewers for participating on the MCH broadcast.

I encourage you to take a couple of minutes and fill out the on-line evaluation form which should appear on your screen.

I would also like to thank our contractor, the Center for Advancement of Distance Education at the University of Illinois at the Chicago School of Public Health for making all this technology work.

We'll introduce other communication strategies in the coming months.

Following today's Webcast as with all the past and future Webcasts there will be an archive of this session on the website probably at the middle -- by the middle of next week.

We encourage you to let all your colleagues know about the availability of the archive.

Our next MCH Webcast is scheduled for Thursday, May 8.

We hope that all of you will join us and encourage your colleagues to do as well.

Thanks again and we look forward to seeing you next time.

We have a question.

Getting in under the wire.

Thanks. Okay.

We have one additional question which I think could be addressed either by Betty or by Gina and Michael if you want to jump in.
The question is, are there guidelines of when to stop trying to breastfeed because the infant is not getting enough nourishment?

BETTY CRASE>> I'll be happy to speak on behalf of the American Academy of Pediatrics.
We really -- as far as the duration of breastfeeding, the academy's policy is for at least one year and as long thereafter as mutually desired.
That is in the optimal situation where all is going well and the circumstances permit and it's just a good situation all the way around.
Of course, if there seem to be difficulties with the breastfeeding, the baby doesn't seem to be gaining adequately, then we encourage the families to be working with their pediatric health professional, either a pediatrician or they might be working with a family physician.
There really would be no other hard and fast rules.
The academy does look for newborns to regain their birth weight by two weeks with no more than about a 7% weight loss.
If there is a greater than 7% weight loss, then mom definitely needs to be working with her -- with her physician on behalf of her baby.
So that's about what I would have to say for that.

GINA CIAGNE>> I would add one thing.
Part of -- not actually part of the campaign but what the Office of Women's Health has is we're working with the national womens health insurance center and we have a 1-800 breastfeeding help line that is a free service that can address a number of questions.
This question I think Betty was correct in saying your daughter-in-law should be working with her -- with the pediatrician to make sure that the baby is not losing too much weight and gaining what he or she needs.
But we do have this 800 number, 800-994-woman.
And it's a free service that women can call.
Women, parents, support systems can call to answer -- ask breastfeeding questions to get resources and materials and referrals.
I just wanted to mention that is a service that we do also.

CHRIS DEGRAW>> Great.
Thank you.
And we have at this point one additional question.
This one addressed to Dr. Kogan.
Is the data from the Children With Special Health Care Needs Surveys available for an individual state to work with in order to address the new children with special health care needs performance measures?

MICHAEL KOGAN>> Let me answer that in two parts.
Yes, you can go to the NCHS website or a link to the MCHB website and the data is currently available there to work with.
You can -- also I would encourage you to sign up for the list serve so you'll get an update when the final data is available with the adjusted weights.
The second point I want to make is that for -- we sent out a table of where the performance measure -- the questions for the performance measures are located on the data file last week, along with a program on how to get the performance measures from the data.

Now, you can work with it yourselves and also another thing is we're going to be -- we're going to be running the program ourselves for each state and putting the data into the block grants.

CHRIS DEGRAW>> Any additional questions?

If that's it for today, we again thank our presenters and the viewing audience.

Look forward to seeing you again on the 8th of May.

Thanks.